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Objects of safety and imprisonment: breathless patients' use of medical objects in a palliative setting

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Abstract

In this paper we consider breathless adults with advanced non-malignant lung disease and their relationship with health objects. These objects include ambulatory oxygen, oxygen concentrators and inhalers, and non-pharmacological objects such as self-monitoring devices and self-management technologies. We consider this relationship between things and people using an interdisciplinary approach employing psychoanalytic theory (in particular Winnicott's theory of object relations and object use), science and technology studies (STS) and phenomenology. This collaborative approach allows us to relate patient use of health objects to ways of thinking about the body, dependency, autonomy, safety, and sense-making, within the context of palliative care. We illustrate the theoretical discussion with three reflective vignettes from therapeutic practice. We conclude by suggesting further interdisciplinary research to develop the conceptual and practice-based links between psychoanalytic theory, STS and phenomenology to better understand individual embodied experiences of breathlessness. We call for palliative care-infused, psychoanalytically informed interventions that acknowledge breathless patients' dependence on things and people, concomitant with the need for autonomy in being-towards-dying.

Keywords (7)

Breathlessness, medical objects, attachment, medical oxygen, technology, phenomenology of illness, end of life.

Introduction

Since the inception of the science and technology studies (STS) movement in the early 1990s, user interpretations of technology have been given increased attention as a way of understanding technology as a product of social construction and social construction as a product of technology. This approach, known as SCOT (the social construction of technology), introduced the concept of interpretive flexibility (Pinch

and Bijker, 1987). According to this concept, technologies can be interpreted in different ways by their users before closure of meaning is attained, if it ever is. Focusing greater attention on users of technology emphasized the agency of these users. It further iterates that the meaning of a technology is not fixed and is not exhaustively defined by its manufacturers. Rather, people give objects meaning through their habitual use and appropriation of the things themselves.

Such an approach has also been utilized within anthropology, where the study of material culture is used to help understand people and their relationships through the objects in their lives (Miller, 2010: 153). This research argues that people ‘create themselves’ with the help of material things. We argue that this is an important phenomenon to consider particularly during difficult periods, such as living with progressive illness e.g. advanced respiratory disease (Turley and O’Donohoe, 2012). The object ambivalence that can arise at such times is reflected on the macro scale in the global movement for health, which ‘both depends upon objects for its own advancement and seeks to tackle objects as the cause of ill health and disease’ (Russell and Widger 2018: 392). Carel has used a phenomenological framework to illustrate how the experience of illness can be transformative, turning navigation of the world, and the use of objects within it, ‘into a strange uncanny experience’ (Carel, 2014: 5).

Thomas (2006) has argued that phenomenology’s critical influence on the study of the human experience of things has been somewhat overlooked within material culture research. However, it is clear that ‘the “things” of medicine have always been present in anthropological inquiry’ (Carroll and Pankhurst, 2019: 2). For instance, scholars such as Duckworth (2019:106) have shown how a cup of tea allows those undergoing palliative care and those caring for them a moment of ‘being in the present’. Indeed, Duckworth suggests that prominent material culture studies have issued a methodological call to ‘know systems of social relations’ by ‘following the object’. Here, we follow the object by exploring the gap between

phenomenological accounts of illness experience and the objects that are part of that experience.

We bridge this gap here by exploring the conscious and unconscious relationship breathless patients may have with the health objects they use to negotiate living with advanced illness. Recent work by medical anthropologist Megan Wainwright (2018) utilises a post-phenomenological framework to emphasise how home-based technologies, such as medical oxygen, mediate and shape the lifeworld of their users. We suggest that Wainwright's conceptualisation of ambulatory oxygen as a 'limiting enabler' relates to a greater variety of respiratory health objects, and a phenomenological framework can help us understand the multiple meanings, interpretations, uses, and relationships of health objects as illustrated by our retrospective clinical vignettes of breathless patients with advanced disease in the UK. In addition, by applying concepts from Donald. W. Winnicott's psychoanalytic theories of object relations and object use, we consider the potential for health objects in adult life to be both facilitatory – a means of creative self-fashioning and engagement with the world – and imprisoning – contributing to a relational experience that is static, constraining and deeply affected by early-life experiences (cf. Leder 2016).

We distinguish between the functional use of health objects ('objects' in the material and practical sense, manufactured and prescribed as health technology) and what Winnicott (1953) describes as 'transitional objects' and 'object use'. These terms originate from his observations that a baby's emotional development is always in relation to the primary object (mother). 'Transitional objects' are special things that enable a safe emotional separation from the primary object and are part of normal human development and creative expression throughout the lifespan.

'Object use' refers less to the properties or function of the object, and more to what it *means* or *represents* to the user; how the object is used to negotiate 'a dimension of living that belongs neither to internal nor to external reality; rather it is the place that both connects and separates inner and outer' (Abram 2018:337).

Contemporary psychoanalyst Christopher Bollas develops Winnicott's concept of 'object use'. For Bollas (1987) the objects we seek and use throughout the lifespan provide deeply felt 'textures of experience' that resonate existentially (rather than cognitively) with early, pre-verbal experiences. These intense experiences impact on how the whole self (what Winnicott (1954) calls 'psyche-soma') negotiates the world and feels it to be real, safe and full of potential rather than unreal, dissonant and unsafe.

We bring STS together with aspects of psychoanalytic theory and phenomenology, to argue that more attention should be paid to the role medical objects play in the lifeworld of people suffering from severe, chronic breathlessness, also termed 'chronic refractory breathlessness'.¹ In what follows we begin with a discussion of health objects used to treat breathlessness and describe the problems associated with their use. Following this we briefly introduce object relations theory (a particular approach within psychoanalytic theory), and then consider how a phenomenology of breathlessness can be used to deepen our understanding of the use of health objects in respiratory illness.

The clinical vignettes we present to illustrate our argument are based on one of the authors' (KB) personal interpretations and observations from therapeutic practice as a music therapist and mindfulness/yoga therapist with patients experiencing severe breathlessness in UK palliative care settings.² These observational data are drawn from KB's recollections of working with patients rather than from fieldwork and have been explored long after clinical work was completed and as conceptual connections with the *Life of Breath* project became apparent.³

This reflective and retrospective approach has been described as an "open systems" process, where theoretical connections are made after events have happened rather than looking for or predicting particular outcomes or behaviours (Ridder, 2005: 166-8). Here, we attempt to understand patients' relationship with their health objects *in retrospect*, and within the unique context of each person's life

and inner world as it was explored in therapy. We use these vignettes to illustrate how a psychoanalytic exploration of the individual's relationship with health objects informed by material culture studies and phenomenological concerns may lead to a richer, less pathological, account of their experience and health behaviors. This approach also generates new questions about how healthcare professionals and providers of health objects may view this complex relationship between objects and people.

Breathlessness: an under-treated source of distress

The experience of breathlessness is created in and mediated by the mind and the body (Booth et al., 2015). The severity of breathlessness is not reliably predicted by disease stage – a discrepancy that is well documented in medical literature and that has led to judgmental terms such as 'disproportionate breathlessness' and 'unexplained breathlessness' (Spathis et al., 2017). The effect of breathlessness on the patient is similar to the experience of chronic pain, which is mediated by the individual's response to the sensation, itself mediated by an often-under-acknowledged web of social, environmental, and individual prior experiences and expectations (Faull et al., 2018). Our consideration of individuals' response to breathlessness and their use of medical objects in modifying that response is motivated in part by Booth, Chin, and Spathis (2015), Faull et al. (2018), Carel (2018), and others' call for an interdisciplinary understanding of, and engagement with, the experience of breathlessness beyond the management of disease pathology.

Many patients living with advanced non-malignant lung disease and chronic refractory breathlessness face unabated feelings of fear of death, giving up, depression, abandonment, isolation and panic (Currow and Johnson, 2015; Carel, 2018). The most common cause of refractory breathlessness is chronic obstructive pulmonary disease (COPD), a progressive lung disease predominantly caused in the UK context by smoking, with a current estimated national prevalence of 1.2 million diagnosed cases and a further 800,000 undiagnosed cases (British Lung Foundation,

2016). As the disease progresses, an uncertain trajectory of sudden exacerbation and recovery, combined with high rates of psychological distress (anxiety and depression), social isolation and social deprivation leads many of these patients, and their family care-givers, to live for many years with poor quality of life, and feel under-supported, often powerless and undeserving of care (Booth et al., 2015; Gysels and Higginson, 2011; Williams and Carel, 2017).

The health objects used by these patients contribute to their psychosocial world and are therefore relevant to any attempt to understand their predicament. The ways in which objects are prescribed, described, received, and utilized require more consideration and ultimately, a reconceptualization, moving from seeing them as pragmatic items with purely medical utility to understanding them as intimately embedded in all aspects of the internal and external experience of the breathless person. As Arteaga (2019) argues in the context of those wearing stoma bags, this type of medical object makes it possible for its users to, 'present an anatomically different body to oneself and to the world'.

Patients with advanced COPD are routinely prescribed items of medical technology to palliate breathlessness. These may include short and long acting inhaled medication (inhalers), ambulatory oxygen, and oxygen concentrators for use at home. Non-pharmacological objects include hand-held fans that are used to reduce the sensation of breathlessness through the flow of cool air on the face, written or digital support such as recorded relaxation, and pacing techniques packaged as 'self-management' strategies. In addition, patients may appropriate measurement tools commonly used by healthcare professionals for personal use, such as oximeters, which patients use to self-monitor their blood oxygen saturation levels. Others may not comply with professional guidance (for instance by not using the inhaler as guided, or smoking around oxygen), or request oxygen from their healthcare provider when there is no proven physiological benefit (Abernethy et al., 2010; Lyons and Chamberlain, 2006).

Although patients' 'visible and invisible' stigma has been acknowledged, for

example in recent work on the hand-held fan (Luckett et al., 2017: 9) and home oxygen use (Breaden et al., 2019; McGuire and Carel, 2019), the tension around meaning and use of such objects is underexplored in the literature and underestimated within the clinical setting. We therefore propose that an individual's disposition towards, and the meaning of, health objects (and their providers) are important factors to be considered beyond the practical function of the object *per se*.

Highly rational cognitive models from health psychology do not adequately capture the complexity of patient and healthcare provider relationships, behaviors, and attitudes around adherence or appropriation of health objects (Pinnock and Sohanpal, 2016). Treatment and behavior change models largely ignore *how* a health technology/object is given and received, and pay little attention to the user's emotional and developmental history, sense of agency, and innate potential for growth and change even towards the end of life. This is practically relevant in the context of healthcare where patient noncompliance can lead to a waste of resources, health professional-patient miscommunication, loss of trust, lost opportunities for a deeper understanding of patients' self and world-views, and unnecessary patient suffering.

Psychoanalytic theory, object relations and healthcare settings

Psychoanalytic literature about life-limiting illness has emphasised the importance of attachment relationships in adults with advanced disease, both in terms of interpersonal processes with clinicians (who themselves represent safety) and between adult couples threatened with change and loss. For example, in dementia, Loporprabhu et al. (2007) describe the transition into total bodily dependence and a psychoanalytically informed therapeutic response that supports the bonds between patient and family. Transplanted organs have been interpreted within a 'transitional phenomenon' framework by Goetzman (2004), who has used this to understand the

symbolic relationship between donor, graft and recipient. The attachment relationship between adults with chronic disease and medical devices has been explored in the context of diabetes by Berk (2018) who has analyzed how human agency is affected by insulin pump usage. Within the context of healthcare environments, the 'quiet' materialities associated with the routine use of hand gels can produce confidence and trust in the 'safe hand' of the healthcare provider (Pink et al., 2014: 433)

However, the intimate relationship between disabled bodies and health objects has been given little scholarly attention within disability studies, a gap that some have attributed to disability studies' tendency to deny 'the phenomenological physicality of the body in its efforts to emphasize the social construction of disability' (Lupton and Seymour, 2000: 1853). One notable exception is Viridi's (2019) analysis of the attachment relationship between 'Toby' the hearing aid and his owner.

In mental health settings, Tutter (2006) has suggested objects (such as oral medication) may 'receive and screen transference projections' so that the thing/pills are 'cyphers for early needs, frustrations and desires' (cf. Leder 2016). Wilson (2005: 19) presents the idea of 'pills as play' within the 'play-space' of a psychiatric patient-provider relationship. In drug addiction treatment, Potik (2007) similarly explores ideas of dependence (addiction) and methadone and its provider as a transitional object to be 'played' with. In this context, 'play' is a psychoanalytic term, used in the following sense. For Winnicott (1980), 'playing is itself a therapy'. It is a creative means of self/other exploration first experienced at the mother's breast, and is, throughout life, a psychic mechanism for finding and allowing the authentic self to thrive. The importance of therapeutic 'play' is – as we shall see – central to our retrospective understanding of patients' relationships with their health objects, described in the vignettes below.

Despite the richness of this psychoanalytic literature, symbolic meanings of health objects and technologies that mediate the reception of oxygen into the body

are underexplored; yet they seem to have a deep importance for the inner and outer worlds of the person using them. We suggest that technologies bringing oxygen into the body have a special symbolic resonance related to fundamental meanings associated with breath (e.g. life, spirit, inspiration). Phenomenologically, these meanings and the experience of their antonyms (death, struggle, expiration) contribute to a gripping and pervasive anxiety that cannot be ameliorated by technology alone. The technology may efficiently regulate oxygen levels but is not able to regulate safety-seeking behaviours, triggered by the affective distress of severe pathological breathlessness (Williams and Carel 2017). In and of itself, oxygen-regulating technology, being an inanimate object, cannot satisfy the need for protection, soothing and reassurance that can only be provided by interpersonal relationship. This 'performance of interactions with them' (Hurcombe, 2008: 537) endows these objects with the materiality of either safety or imprisonment. If we refer to Winnicott's ideas on *the play of interpretation*, it is in the mother/healthcare provider's 'willingness to help [...] to identify with the patient and so to believe in what is needed and to meet the need as soon as the need is indicated' that matters to the patient. This is what constitutes care, which is *interpretative* and not merely functional, pre-emptive and prescribed (Winnicott, 1958).

It has been suggested in the health psychology literature that a psychoanalytic perspective on responses to chronic illness may help understand why some patients are more distressed than others when experiencing pain, for example (Pietromonaco et al., 2013). We propose that these perspectives have an underexplored relevance in understanding, assessing, and treating the varying and complex affective responses found in patients experiencing refractory breathlessness. Distress and anxiety are often downplayed by health professionals or classified as separate entities: a mental health co-morbidity, despite qualitative evidence that breathless patients need to explicitly communicate the seriousness of their experience and feel frustration and distress at not being heard and understood (Harrison et al., 2014). Williams and Carel (2017: 152) analyse the 'primordial, interrelated, and mutually impacting features' of anxiety and breathlessness, and

the lack of routine access to person-centred, integrated care. The important links between anxiety and breathlessness have also been noted in neuroimaging studies (Faull et al., 2017), which show how individual psychology and past experiences affect the neurological processing of breathlessness.

Phenomenology of breathlessness

A phenomenology of illness (and particularly of breathlessness) has been developed in recent years to illuminate experiences of bodily and mental pathology from an experiential, nonmedical and nonreductive perspective (Ratcliffe, 2008; Carel, 2016; Svenaeus, 2001; Toombs, 1993). On this view, the lived experience of illness cannot be reduced to a biomedical account of disease, or even a psycho-socio-biomedical account. Medical accounts exclude the ways in which the ill person's lifeworld changes, including the experience of space and time, and the geography and social architecture of the ill person's lifeworld (Carel, 2018). Illness can also instigate existential change, where routines and habits, values and attitudes need to be reconceived considering the limitations of illness, including a poor prognosis. This existential change is deep and pervasive (Carel, 2016). This process reaches a new level of challenge and intensity in severe or end-stage disease, as explored in the hospice-based clinical vignettes below.

Phenomenologically, breathlessness has several unique features. First, breathlessness is a unique bodily function that is automatic but can be overridden with conscious modulation. Patients suffering refractory breathlessness may feel guilty or responsible for their symptom and may feel that they ought to be able to control it better. We suggest this contributes to both a tendency towards what has been termed 'professional nihilism' and patients downplaying their symptoms even in very advanced disease (Pinnock and Ratna, 2016). Breathlessness is also intimately connected with our emotional state and mood, so can cause severe

anxiety and distress. This explains why breathlessness feels so distressing: it is experienced as a threat to one's emotional and physical wellbeing.

Breathing is also deeply connected to our notion of life. Difficulties breathing are experienced as a threat to life. This intimate connection dominates people's experiences of breathlessness: they describe it as frightening, akin to suffocation, or drowning, and as overwhelming and deeply distressing. This severe distress has been shown to activate the same brain pathways as pain, hunger, and thirst. Breathing is a vital bodily function whose restriction leads to dramatic sensations of distress, panic and overwhelming anxiety (Herigstad et al., 2011). Living with repeated cycles of extreme breathlessness, followed by attempts to calm oneself and slow one's breathing – seen as the regaining of control – can cause a gradual assimilation of these panic states which can become more pervasive and globalized, leading patients to suffer a vicious cycle of deconditioning and self-imposed limitations. Those suffering from refractory breathlessness need to be situated within their own history of increasing breathlessness, and sense of helplessness. This sense of helplessness is also seen in health care professionals' attitudes to refractory breathlessness, which is often characterized by a sense of futility, given the limited interventions for breathlessness (Currow et al., 2014).

Phenomenologically speaking, the world of the breathless person shrinks, both metaphorically and concretely, to the extent that the breathless person can feel imprisoned. Geography changes: mounds become hills, and hills unscalable mountains. Distances that were once within easy walking distance now require transport. Fatigue can make even a short outing into an ordeal, and anxiety can reduce confidence and cast dark hues on outings intended as pleasurable. The metaphorical shrinking is also affected by worries about possible problems (like running out of oxygen or becoming exhausted), reduced levels of activity and energy, and an attenuated sense of engagement with the world (Carel 2016).

The natural modulation of breath, which adapts the rate and depth of breathing to exertion level, is now artificial and the object of anxiety and explicit

attention, as we will see in the clinical vignettes. Since this engagement is fraught with anxiety, a sense of lost abilities, and fear of future deterioration of lung function, it accompanies the breathless person's everyday with ongoing concern and worry. A new, breathless, body replaces the previous habitual body and this ongoing concern with breath, its absence, shortness, or restriction, and the relative poverty of means of alleviating this breathlessness feature overwhelmingly in day to day experiences.

The preoccupation with breathing, saturation levels and lung function is not restricted to the ill body. It becomes increasingly dominant and inflects patients' relationships with the medical technologies offered to alleviate breathlessness. The same negative attention, anxiety and hypervigilance that characterizes breathless persons' attitudes towards their own bodies also characterizes their attitudes towards the technology. Such negative feelings towards assistive technology are closely linked to wider social issues, including the stigma linked to appearing in public with oxygen. Concerns over public reactions can result in wholesale rejection of this technology, especially because breathlessness is made visible through its usage and forecloses the ability of its users to 'pass' as 'well' (McGuire and Carel, 2019). In the same way that safety behaviors develop to reduce anxiety about breathlessness, exertion, being in public and outings, analogous 'irrational' behaviors develop towards the medical technology.

One example of such seemingly irrational behavior is hoarding of oxygen equipment at home. Oxygen companies conduct regular audits of the equipment patients have at home, removing excessive equipment beyond the prescribed amount. But as far as we are aware, no attempt has been made to find out why patients hoard oxygen equipment. Once safety becomes paramount, as we propose here, the behavior becomes understandable. The fear of running out of oxygen, the delivery not coming on time, or being restricted in one's activities because of lack of oxygen, may motivate hoarding behavior.

In the next section, we present three clinical vignettes from KB's therapeutic practice, illustrating that the meanings patients attribute to, and their disposition towards, health objects, focus more on establishing a felt sense of safety via interpersonal process than achieving objective physical symptom reduction, although it is acknowledged that the two are deeply intertwined (Booth et al, 2015; Pattinson et al., 2018; Faull et al., 2018). We use the three theoretical approaches presented here, psychoanalytic theory, STS and phenomenology, to interpret the vignettes.

Through Winnicott's lens, *things* (here objects of health technology) act as a *defence against anxiety*. This object relationship is clearly expressed in Berk's relationship with her insulin pump, 'I am not panicked that my pump will not be with me; I just feel better when I can touch it and see it, and make sure that it is there' (Berk, 2018: 454). It is not to be taken away or tampered with, just like the toddler's comfort blanket that can't be washed and is carried everywhere (Winnicott, 1953). The 'good enough' healthcare provider understands that the object may have meaning beyond functional status. It is understood that the object (and its provider) must be reliable and consistent until the subject does not need it anymore, which is at a time of their own choosing. Of course, in a medical context this is not always possible or appropriate but may explain mutual frustration of both healthcare practitioner and patient over discontinuing or changing treatment objects and regimes, for example, in cases of the removal of home oxygen.

Clinical vignettes and discussion

Clinical vignette 1: 'Gwendolin' An Oxygen Cylinder⁴

It is common practice for people to name machines. We tend to anthropomorphise tools that we need to place our trust in as female; from sailboats to Siri and Alexa. Similarly, Brooks has written about his relationship with his home oxygen machine, Fifi: 'The pair of us are joined in mock matrimony by a length of black hosepipe [...]

We have been sleeping together for about six months' (Brooks, 1992: 96). Pam's story is similar.

Pam attended a hospice for about a year before her death from COPD. She lived alone and although she had adult children, she felt isolated and continuously anxious which led to a GP referral to day hospice support once a week. Pam's anxiety was difficult for staff to remain empathic towards. Everything to do with Pam seemed to take a lot of time and energy. There was a sense that she was 'attention seeking' and, after some unsuccessful attempts at cognitive behavioural techniques (Pam became more anxious at failing to understand something she found complicated) and a trial with a hand-held fan (which she kept losing) she was referred to music therapy. Pam came to these sessions in a wheelchair. She had named her oxygen cylinder Gwendolin and it took two people to get her anywhere: one person pushing the chair, another wheeling the heavy metal cylinder which impeded Pam's freedom significantly. However, Pam talked about Gwendolin as if she were a loved but slightly annoying pet: 'Mind Gwendolin, she does get in the way!' Pam had knitted a colourful woollen cover which she put over Gwendolin once she had settled into position. This made 'her' *look softer, pretty*. She touched and played with Gwendolin constantly; checking the oxygen flow, tucking in the blanket, sorting out the tubing.

It was clear that Pam's anxiety became much worse if she anticipated a potential problem with Gwendolin – if there might be a glitch with cylinder delivery or with accessing the smaller, portable cylinders (which meant that going out for the day might be impossible). This anxiety kept Pam awake and exacerbated her breathlessness. That the strength of attachment to an object is exacerbated due to the threat of incipient loss has been acknowledged by others, for instance in Pankhurst's (2019: 91) study of itinerant worker's attachment to their passports, which was strengthened because of the passport's 'potential as a material failure'. Perhaps the sessions – rather like the care provided by Winnicott's 'good enough'

mother – would provide the opportunity for communication, interpretation and recognition of some as yet unexpressed and unsatisfied need.

During the sessions it became apparent that Pam's early life had been difficult. Something in Pam's behaviour made KB think of a toddler's insistent, unsatisfied calling that could be related to Winnicott's idea of the *First Feed*, the summation of the early experiences of many feeds (Winnicott, 1988). Without this primary, reliable experience as an early psychological building block, a person may be consigned to being trapped in a state of need. It did indeed feel as if Pam was stuck, crying out for something that the staff could not quite understand or provide.

In therapy, KB therefore focused less on the litany of problems and worries associated with now and the future, and more on Pam's felt sense of security which was, and had always been, absent. Her earliest relational memories were of her father's death when she was a young child, a difficult relationship with her mother and subsequently her two husbands, both of whom had died. Gwendolin was frequently checked and touched during these sessions (Pam's transitional object) until, gradually, Pam was able to slow down, relax her body, and rest back into her felt experience without constantly talking. It was as if she had run out of anxiety defences and could begin to feel safe within the therapeutic relationship.

'I need security to survive, yesterday, today and tomorrow', were the words of the song Pam wrote in therapy towards the end of the work together. It was only via a process of co- (with the therapist) and then self-regulation of her fearful inner state that Pam was able to find, name and communicate her inner world and unexpressed needs. The therapy offered Pam an integrative experience that she had missed out on in her earliest life: '*Quiet* experiences [...] [she] needs to feel held lovingly, that is, in an alive way, yet without fuss, and anxiety and tenseness' (Winnicott, 1949: 233). Thus, by relaxing into creative 'play' during therapy, she began to know herself, mourn her past, and accept her future. Pam moved on from her transitional object (Gwendolin-as-pet), became less anxious and died well a few months later in the hospice. Gwendolin – the 'limiting enabler' (Wainwright, 2018) –

was Pam's *not-me object*, representing a longed-for sense of safety but imbued with anxiety, which was Pam's inner reality. Gwendolin literally and symbolically mediated Pam's experience of herself and her environment. As Winnicott (1953: 232) explains, 'the object is one of the bridges that make contact possible between the individual psyche and external reality.'

Clinical vignette 2: iPad as a digital transitional object

Bill was in his early seventies and had lived with steadily worsening COPD for many years, experiencing chronic breathlessness that impeded his mobility, sleep and quality of life. He lived alone with very little social support outside healthcare services. In contrast to Pam's high emotional reactivity, Bill engaged very little when he attended hospice day services, sitting alone in a corner and eating separately from the other patients although he regularly attended the 'mindful yoga' therapy group run by KB. He had never attended pulmonary rehabilitation. Over the winter (as is often the case with COPD patients) Bill's condition worsened and his breathlessness and distress caused him to call 999 or 111, especially at weekends and at night, resulting in multiple hospital admissions. He told KB he panicked at the thought of being alone with the horrible sensation of overwhelming breathlessness, and that in hospital, with people around him, he felt safe again. He said that he felt immediately better when he saw the ambulance draw up outside. Just to see the green uniforms of the paramedics calmed him down.

After his requisite twelve weeks in day hospice Bill was discharged, but swiftly re-referred by the respiratory team. He had been hospitalised almost every weekend and needed more supportive care as his condition deteriorated. Bill had been living quietly at the edges, with little money and increasingly restricted mobility. As time went on, he became more depressed, isolated and frustrated. *Why can't they do anything?* But Bill had learned to expect very little from anyone or anything. Being breathless and lonely was a way of life.

Bill wanted to look after himself, but when the breathlessness, coughing and fatigue (he was not able to lie down to sleep) triggered him into fear and panic he activated the only protective system he knew would be available, the emergency services, to regulate his psychophysical distress. He felt guilty about this; he did not want to waste anyone's time or bother people, but things kept getting so bad that he had no alternative than to press a metaphorical panic button.

At day hospice in the mindful yoga therapy group Bill's breathing and affect reliably improved. He told staff it really helped him to feel calm. However, calls to out of hours services and hospital admissions were still frequent when Bill's sense of isolation was at its worst. Evidence shows that in chronic COPD higher levels of structural social support increase activity levels and reduce psychological distress (Chen et al., 2017). But Bill couldn't magic a caring family out of nowhere.

Bill's response to threat (lack of engagement, self-reliance) had protected him well enough for most of his life but was no longer working. He was in a frightening transitional stage towards dependency and death. How could Bill be provided with some form of support that might help him develop his own inner resources to self-regulate what KB felt was natural distress? The gold standard treatment for 'psychological co-morbidity' is currently cognitive behavioral therapy, but there is a lack of evidence for effectiveness in the population to which Bill belonged: older and with end-stage disease, poorly educated, lacking social support, with low confidence and self-efficacy (Sheree et al., 2014).

The response was to lend Bill an iPad onto which KB had recorded short, personalized practices aiming to complement the work they were doing together each week. Recorded directly to camera, using his name, gently encouraging and supportive, the techniques did not aim to explicitly interrupt cognitive processes and challenge dysfunctional thoughts, but to target the symptoms themselves directly via a 'bottom up' body-based approach. Bill was given different videos he could use at home: a 'dose' for daily practice and one for those difficult, lonely times when he could feel the anxiety and breathlessness rising. The iPad would – KB

hoped – provide Bill with a safe transitional object offering almost-real human contact.

This digital transitional object did, in fact, reduce Bill's admissions to hospital. Interestingly, the first couple of times he could not get the volume right, and said he had used the silent film anyway, which had made him feel better. Just the non-verbal, virtual, moving, smiling, encouraging *image* of a 'good enough' object had a powerful soothing effect.⁵

The story has a sad ending. Eventually Bill was discharged from the day hospice and the iPad was removed (against his will) due to the strictures of service provision. He died a few months later in hospital.

Clinical vignette 3: The oximeter as a safety object

Experiential relationships with self-tracking objects have been conceptualised by the post-phenomenological literature (Wainwright, 2018) as hermeneutic relations. The data produced by the object is interpreted by the user in a particular way, here as a 'checking' device.

Joyce was in her early sixties and had been waiting for a lung transplant for many years. Frequent infections had prevented the surgery at least once, and Joyce's time was running out. She had bought an oximeter on the internet and wore it clamped to her left index finger most of the time. She constantly checked her oxygen saturation and pressed those around her to confirm the oximeter reading and validate her breathlessness. This object represented a continual question: *'Am I safe?'*

Attending the day hospice for weekly respite, Joyce was referred to music therapy for emotional support while she was on the waiting list for a lung transplant, a time acknowledged to be uncertain and existentially challenging (Ivarsson et al., 2013). In therapy, Joyce revealed a deep lack of self-esteem caused by early childhood neglect and compounded by her current relationship with a man

she described as frequently drunk and abusive. She said he wasn't interested in her and didn't care whether she lived or died, but Joyce almost waved this away, as if her physical safety wasn't important. KB reflected on the work of trauma specialist Bessel van der Kolk (2015) who asks: 'How do (traumatised) people learn what is safe and what is not safe, what is inside and what is outside, what is resisted and what can be safely taken in?' KB felt that Joyce was similarly dissociated when talking about her unsafe home environment. Joyce had not made the connection between her early childhood experiences and her current situation. She was anxious about her oximeter readings but not about danger to her body and mind from within her home.

After several sessions where a therapeutic relationship was established, KB carefully enquired whether Joyce might remove the oximeter and listen to her body. Would she be able to sit, breathe and evaluate her actual felt experience? And indeed, just to sit quietly with the therapist with her hands resting on her belly and chest was a profound and novel sensation for Joyce. Supported by the therapeutic relationship, she could experience a moment of what Malpass et al. (2018) describe as 'informative bare attention'; an increased perceptual evaluation of her breathing and body sensations, as opposed to a habitual, fear-based pattern of thinking and feeling laid down in childhood and perpetuated in adulthood by domestic abuse. She found that her breathing was, in fact, in this moment, OK. Joyce was able to go on to explore what Winnicott (1953) described as 'the boundaries and solidity of [her] Bodily Scheme [...] which [she] had given up at an earlier period in [her] life when the duality psyche-soma began'. Over subsequent sessions, body- and breath-based integrative practices led to the creative use of music and song to explore Joyce's feelings about her past, and questions about her future. The question was still often '*Am I safe?*'. But the answer was increasingly: *in this present moment, I am safe* and the oximeter (checking device) was no longer needed.

The relationship between such validation of experience and self-tracking that Joyce's case illuminates has been given increased attention in recent years (Neff and

Nafus, 2016; Neff and Fiore-Gartland, 2015). This is linked to the increased popularity of self-tracking devices which are now often embedded within mobile phones or watches. Indeed, the popularity and viability of these devices means that they are being integrated into health policy measures (McManus et al., 2018). The use of such digital objects to support and foster behaviour change in patients with chronic illness is an emerging interest (Mitchie et al., 2017). For example, in Berk's article about her relationship with her insulin pump she explains that 'I feel better, more balanced, ready to begin my day, when my meter reads within the healthy range.' (Berk, 2018: 454). However, the highs and lows of blood sugar can (usually but not always) be distinctly felt by an experienced diabetic, whereas the nature of breathlessness poses critical challenges to self-measurement, as well as clinical measurement, as we can see in the case of the oximeter.

Given the invisibility and unclear symptom correlation related to low blood oxygen saturation, use of an oximeter may be embraced to provide an apparently objective and trustworthy numerical validation of experience. However, the unity between the number and the experience is not always validated: its appeal lies in the fact that it allows for single number data which stands in for a complex personal experience. But the substitution remains incomplete. The resultant feeling of control may be particularly important for people experiencing breathlessness as a *lack of* control and distrust of one's own body (Carel, 2013). Achieving greater control over our lives and bodies has been identified by several scholars as one of the most important explanations of our wider embrace of self-tracking (Smith and Vonthehoff, 2017).

Of further note in the case of Joyce's oximeter use and self-tracking is the problem of disjunct between data and experience. Smith and Vonthehoff argue that 'bodily intuition is being outsourced to, if not displaced by, the medium of "unbodied" data' (2017: 7). Their claim is that self-tracking leads to distrust in the body and suppression of embodied experience. However, in Joyce's case we see the opposite causal process, where a lack of trust in one's body leads to self-tracking. As

we can see from the outlined clinical vignettes, the complex interaction between person, body, past, health provider, and technology, can give rise to different forms of mistrust, that can be experientially articulated using a phenomenological approach (Carel, 2013).

Conclusion: directions for future research and practice

This paper deployed a trio of theoretical approaches – psychoanalytic theory, science and technology studies, and phenomenology – to shed light on the relationship between patients living with refractory breathlessness and the medical objects used to support them. We illustrated that the embodied experience of such patients may be characterized by fear and safety-seeking, and that despite the considered use of medical technology such as ambulatory oxygen and other objects, attention should be paid to the complex, important, and ambivalent relationship patients may develop with these technologies.

This relationship contains within it patterns of behavior developed in early object relations. Understanding it as such can offer therapeutic benefits to patients, as well as illuminating possible avenues for improved clinician-patient relationship and the effective use of medical objects. Health objects are not just ‘things’ to mechanistically ‘treat’ people. They have deeper meanings for patients that are currently overlooked by clinicians, policy makers and manufacturers whose focus is ‘fixing’, function and cost-saving within pre-existing models of care.

This paper provides a starting point for research with breathless patients using health technologies, their families and professional caregivers in order to better understand patients' needs, improve communication (and clinical compliance) and develop interventions and approaches that maximize the benefits of contemporary health technologies. By describing a possible relationship between early adverse experiences, emotional development, and how individuals relate to living with technologies for breathlessness, we highlight the need for more research

into the links between emotion regulation patterns and variations in symptom severity that have been largely ignored or met with a sense of helplessness and nihilism in medical contexts (Kirkengen, 2010; Anda et al., 2008).

Future research should, in addition to a pragmatic stance (*what works?*), take from this paper the importance of a hermeneutic approach to hypothesis generation, based on observations and reflections about individuals, their inner world and the meaning of their experiences. We suggest that non-pharmacological breathlessness intervention research should explore phenomenological and psychoanalytic concepts alongside cognitive behavioral and neurophysiological models in order to fully understand the internal world of breathless patients.

Existing psychological models explain the vicious cycle of breathlessness-fear-breathlessness as a commonplace part of pulmonary rehabilitation and other breathlessness management approaches (Spathis et al., 2017). However, what these models and psycho-education interventions overlook is that breathlessness represents a disruption to a *continuity of being*; a dissonance between a felt inner world (*psyche*) expressed non-verbally through the body (*soma*) and the environment (Winnicott 1954). By acknowledging this relationship, we can address the need for holistic education of healthcare professionals, caregivers, and patients about living well with breathlessness and the objects used to mediate it. Finally, we highlight the potential for creative body-based therapeutic approaches for patients living with chronic breathlessness. As our clinical vignettes have shown, the lived experience of breathless and disabled patients with difficult pasts and uncertain futures can be transformed with sensitive and attuned person-centered care.

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Notes

1 We use the term ‘chronic refractory breathlessness’ to refer to ‘breathlessness daily for 3 months at rest or on minimal exertion where contributing causes have been treated

maximally.’ The authors note that ‘prevalent aetiologies include chronic obstructive pulmonary disease, heart failure, advanced cancer and interstitial lung diseases.’ R. Wiseman et al. 2013. Chronic refractory dyspnea: evidence-based management. Australian Family Physician 42(3).

² All names and identifying details have been changed to strictly protect patients’ anonymity. Ethics approval to present the vignettes here has been granted by the Faculty of Arts Ethics Committee Chair, University of Bristol.

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⁴ All names and identifying details presented in the vignettes have been changed to strictly protect patients’ anonymity. Ethics approval to present the vignettes here has been granted by the Faculty of Arts Ethics Committee Chair, University of Bristol.

⁵ The potential for complementing face to face therapeutic strategies is ripe for research particularly with isolated breathless patients frequently presenting to A&E.